



**Testimony of Victoria Veltri
State Healthcare Advocate
Before the Human Services Committee
In support of HB 5918
February 19, 2013**

Good afternoon, Representative Abercrombie, Senator Slossberg, Senator Markley, Representative Wood, and members of the Human Services Committee. For the record, I am Vicki Veltri, State Healthcare Advocate with the Office Healthcare Advocate (“OHA”). OHA is an independent state agency with a three-fold mission: assuring managed care consumers have access to medically necessary healthcare; educating consumers about their rights and responsibilities under health insurance plans; and, informing you of problems consumers are facing in accessing care and proposing solutions to those problems.

Thank you for the opportunity to comment on HB 5918. This initiative represents an important acknowledgement of the needs that children with severe disabilities and their families are faced with on a daily basis. By including private duty nursing for these most fragile citizens as a benefit of Husky B, these children can receive the benefit of timely and appropriate care and intervention. Although this need is not widespread, for those few children with severe disabilities, the need for intensive and skilled care in the home is paramount to maximize optimum outcomes. Many of these children arrive home requiring a ventilator, suctioning equipment, a pump for feeding, a monitor for their oxygen level, etc. But most importantly, they need skilled nurses to monitor and care for them. Although parents may be trained to provide some of this care for their sick children, they are not trained clinicians. It is unrealistic to expect them to provide this level of care on a continuous basis. Skilled nurses supplement these children’s support system, ensuring that critical signs are not missed and that care is delivered in a timely and appropriate manner.

Given the fact that many families with severely disabled children must also balance work and home responsibilities, as well as care for other children in the home, the inclusion of skilled nursing in the home as a benefit under Husky B serves as an important barrier against disaster, should the sick child suddenly have a medical crisis. By enabling these children to continue to receive the appropriate level of clinical care once they go home, private duty nursing can also avoid unnecessary readmissions by managing complications in the early stages and in the home.

The cost of private duty nursing is about the same as it is to have a child stay in the hospital. However, by providing appropriate skilled care in the home environment, children may evade avoidable readmissions, realize better outcomes and avoid exposure to hospital acquired infections, so by providing the needed level of care in the most appropriate and least restrictive environment possible, there could be significant savings realized through the avoidance of additional illness.

Over the last couple of years, many private insurers have either removed private duty nursing as a covered benefit or significantly reduced access to this benefit, and our office has assisted many families as they have struggled to meet the conflicting demands of caring for a sick child, other family members, work and coordinating and navigating their insurance benefits. In its place, some insurers provide for home care, which provides a maximum of four hours of skilled nursing care per day, often with a maximum number of visits per year. This benefit is almost useless to a child with complex needs.

One family that OHA has advocated for has a small child with serious medical complications requiring tube feeding and constant assessment and evaluation of her respiratory status, which is frequently complicated by the feeding itself. This child's ongoing private duty nursing benefit was denied by the carrier, leaving the burden of managing her complex needs on the family. Although we were able to restore some portion of the care she was receiving while we appealed the denial, her parents struggled to balance their other children's needs with the clinical needs of their sick child. As a result, her ability to receive and retain nourishment via her feeding tube was impacted, she lost weight and came very close to needing an advanced and more costly clinical intervention that could have been avoided had she been receiving the appropriate level of care all along.

Sadly, this is not a unique circumstance. We routinely encourage parents with babies having special needs to enroll in Katie Beckett. However, the waiting list for an open slot on this waiver is several years long. Accordingly, we also encourage the expansion of this important waiver.

Not many families will need these services, but for those few that do, the addition of private duty nursing as a covered benefit could mean the difference in their ultimate outcome and ability to overcome the challenges that they face.

Thank you for providing me the opportunity to deliver OHA's testimony today. If you have any questions concerning my testimony, please feel free to contact me at victoria.veltri@ct.gov.